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CLOSING THE GAPS IN THE YEARS AHEAD.

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IN A SPEECH AT THE 17TH ANNUAL CONVENTION OF THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN, THE EXECUTIVE DIRECTOR'S 1966 REPORT OUTLINES GAINS AND EMPHASIZES SHORT-RANGE SPECIFIC NEEDS AND GOALS FOR THE FUTURE. ISSUES REQUIRING SPECIAL ATTENTION ARE ARCHITECTURAL PLANNING, THE LAW, AND FORMS OF GOVERNMENT ORGANIZATION FOR WHICH CRITERIA ARE PROVIDED. THE ROLE OF RESEARCH IN THE PREVENTION OF RETARDATION AND THE FUTURE ROLE OF THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN ARE REVIEWED. THIS PAPER WAS PRESENTED TO THE ANNUAL CONVENTION OF THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN (17TH, KANSAS CITY, MISSOURI, OCTOBER 21, 1966). (JW)

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by

Luther W. Stringham
Executive Director

NATIONAL ASSOCIATION FOR RETARDED CHILDREN

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A Report presented to the Delegate Body at the Seventeenth Annual Convention of the National Association for Retarded Children, Kansas City, Missouri, October 21, 1966

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Again it is my pleasure, for the third time, to report to the NARC delegate body. Last year, as in 1964, I took this occasion to review the accomplishments of the NARC staff in performing our assigned responsibilities. I described the steps that had been taken to provide better services to our State and local units, to foster a spirit of unity, and to define objectives for the combined energies of volunteer and staff.

Again this year the temptation is great to outline the forward steps of the past year. As you can see from the 1966 Annual Report, there has been progress in Closing the Gaps. We could review the successful involvement of our people throughout the nation in comprehensive planning, promotion of measles vaccination, creation of new job opportunities, membership development, and securing Federal action to promote day care.

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I could tell you of disappointments, as well, for there were areas in which results did not measure up to our own aspirations.

Rather than dwell on the accomplishments and shortcomings of the past, however, Mr. Tucker has asked that this report be devoted to what, in the judgment of your Executive Director, will be principal problems and needs in mental retardation in the years ahead, and the ways in which NARC can in the future be most effective in further Closing the Gaps.

THE COMPREHENSIVE STATE PLANS REVEAL IMPORTANT GAPS

I now have had an opportunity to study the comprehensive plans of some 35 States. These reports, plus scores of supporting documents, represent the efforts of at least 2,000 professionals and lay leaders in identifying gaps in services and in recommending improvements. Although the plans vary a great deal in scope, content, and originality, there emerges from them a reasonably consistent pattern. In brief, they show clearly that in spite of important advances in recent years we still have far to go in providing the full array of services and facilities that should be available.

. Satisfactory diagnostic and evaluative services still are not accessible to all. The adolescent and the adult are often slighted. Persons in rural areas frequently are missed.

Even for young children these services are insufficient to meet the need. The clinics are too widely separated, and the waiting periods often are long, even where accessible facilities exist.

. There is a great need for case finding and early treatment for the mildly retarded. Children who showed neurological impairments at birth or whose arrival in the world was associated with more than usual complications need to be followed and given special attention.

. In residential care, the predominant pattern is still the large isolated institution in which the programs too often reflect limited expectations. Overcrowding persists, and the care of some residents is still a shame on our society. There is only just emerging the variety of community facilities that will bring living for the retarded to new plateaus of dignity and convenience. Places for residential living, especially for adults who with some supervision can live and work with large measure of independence, exist only here and there across the nation. Standards for all types of residential care facilities and systems for accreditation are urgent needs.

. In education, programs tailored to the needs of the mildly and moderately retarded children are still not available to the large majority. There is so much to be done to make sure that instruction, both in public and private schools, is

by qualified teachers, in satisfactory classrooms, with suitable teaching materials. Retarded children benefit most from a curriculum that is frankly oriented to self-care; physical education; work abilities, attitudes and skills; mobility; and conduct. One must ask with blistering forthrightness: Why are there so few secondary school programs that meet these criteria? And where are the vocational educators?

. One particular area of need in special education is with respect to the moderately retarded, to those the educators refer to as "trainable" children. Much study is needed of existing programs and of the extent to which they are fulfilling the educational needs of these children. The formulation of better programs for them and their adoption by the public schools are urgently needed.

. Vocational rehabilitation agencies now are serving thousands, but many more candidates for employment need services. These larger needs will be met only through life-oriented special education curricula, teaching materials and teachers versed in vocational education and guidance; coupled with employment services equipped to handle the counseling and placement of mentally retarded persons.

. When education and the employment services are performing well, the rehabilitation agencies can be expected to devote most of their energies to those who cannot proceed

from school to job without a good deal of extra help. We look to the time when retarded persons with speech, sight, hearing, emotional, orthopedic and other conditions can receive promptly the rehabilitation services that they need and at as early an age as possible. The multiply-handicapped and those among the lower reaches of the employable groups should be the principal recipients of rehabilitation services

. Though workshops have increased in number, they still have far to go before they represent a fiscally sound network, with quality workshop programs adequately serving as supplements to school, as transitional sites for training and rehabilitation, and as places for long-term employment of the seriously retarded worker.

. The principle is well established that the retardate often does best when he has the security of his own home and the affection of his family. Yet the complex of supportive services needed for retardates at home is lacking in most communities. Day care, leisure time programs, homemaker, nursing, and protective services are generally unavailable to most families from private or public agencies.

These are not all of the gaps that are revealed in the comprehensive plans. Some of the plans deal with the problems of deprivation, inadequate maternity care, and the need for many specialized services. Even an incomplete summary

of their contents shows, however, that a full array of services--the continuum of care for which we have so long worked--is only beginning to be achieved. In the coming years, especially the next two or three, we must work hard for the implementation of these plans.

But we must do more than catalogue generally recognized needs. There are other issues to be faced which were not adequately dealt with in the comprehensive plans. I will now discuss three of them; namely, architectural planning; the law; and forms of governmental organization.

ARCHITECTURAL PLANNING

Here and there across the land are appearing structures that reveal creative relationships between program and structure. But they are the exception. More often we see construction to provide custodial care rather than habilitation. Large institutions are conceived as asylums, hidden away, with no opportunity for normal indoor and outdoor life for the residents. Facilities are still being planned where residents cannot see outside from the living areas. Statistics show a definite decreasing trend in the combined per resident space allotted to activity, play, and day rooms. It is a shocking fact that today less space is being provided for resident activities than

in 1957.

Through its Architectural Planning Committee and its staff consultants, NARC has propounded principles of care and the necessary relationship to them of sound planning of structures. It is the architect, we emphasize, who must plan the environment in which retarded persons live, are trained, receive care, study and work. He must provide the proper image of these facilities to the user and to the public so that buildings become instruments of treatment rather than cells of custody. He must recognize that architecture has a large role to play in the creation of facilities which not only permit, but enhance rehabilitative opportunities. We also must have enlightened administrators with a desire to create new and improved programs of habilitation and care. We must have a cross fertilization of ideas between architects and program experts.

In the years ahead we have far to go in the area of architectural design. An action program of major proportions is urgently needed to interest more architects in mental retardation; to acquaint them with program concepts; to expound on the interrelationships between structure, resident, and community; and to publish more adequate guidelines for design. NARC should be the catalyst, working with the American Institute

of Architects, the American Association on Mental Deficiency, schools of architecture, the Public Health Service, and other agencies in bringing about a new day for new construction.

THE MENTALLY RETARDED AND THE LAW

Modernizing the law as it affects the mentally retarded is one of the most complex of the problems that we face. Basic issues were presented in 1962 by a Task Force of the President's Panel, and an elaborate study project subsequently was established at the National Law Center of George Washington University, under a Federal grant from the National Institute of Mental Health. Existing laws and their operations are being analyzed from many points of view and guidelines for new legislation will be proposed as the study comes to a close in 1967.

Improving legal measures to meet the needs and to protect the rights of retarded persons involve many aspects--civil, criminal, and programmatic. In the area of civil law fall such matters as guardianship of the person and his property, marriage, sterilization, voting, contractual rights, and commitment. In the criminal law fall such critical matters as capacity to stand trial and criminal responsibility. The archaic terminology and definitions that prevail in law at all

levels of jurisdiction are basis for alarm. For the most part, they reflect antiquated concepts of criminality, eugenics, and social responsibility.

Most of the legal provisions in such program areas as protective services, education, health, and prevention are out-of-date or absent.

To say that obsolete laws are unenforced is not good enough--the law should be a living part of our total effort, keeping in step with modern concepts of care, habilitation, and community acceptance.

NARC must accept a larger interest in matters relating to the law; for we are setting in motion forces--such as employment programs--that will bring into sharper focus the individual responsibility of the retarded person as a private citizen and the responsibilities of society toward him.

FORMS OF GOVERNMENTAL ORGANIZATION

The growth of Federal and State mental retardation programs makes necessary a careful consideration of the best forms of governmental organization. There now are divisions or offices of mental retardation in State health, mental health, institutions, and welfare departments. Program coordination is being sought by various means, such as interagency commissions

or committees. There is no consensus as to what is the best organizational structure; and in view of the diversity of financial, political, and legal conditions within the States, a single best form cannot be recommended.

There is, however, a growing consensus as to the criteria that must always be met regardless of the precise locality of statutory responsibility, if the mentally retarded are to receive the attention that they need and to which tney are entitled. These criteria are as follows:

1. There must be specific formulations of responsibility. Every agency should be required to spell out how its program, under present authority, does and could help to meet the needs of mentally retarded persons. There should never be any doubt as to the legal responsibilities of health, mental health, education, welfare, rehabilitation, recreation, and employment agencies.

2. These specific responsibilities must be assigned to identifiable organizational units within the larger structure of government. Depending on the array of functions it might be a bureau, or division, section, or desk. But it must be visible; we must be able to find it!

3. The responsible organizational unit must be staffed--staffed with interested and qualified people. These

are the people with responsibilities for program implementation with whom we can and must work.

4. These people must have money to spend to carry out the programs for which they are responsible. These funds must be identifiable and there must be an accounting for their investment in programs for retarded persons.

5. Finally, beyond all these individual efforts, provision must be made to promote both interagency cooperation and the initiation of properly-timed comprehensive reviews of the totality of effort and recommendations for further program development.

As we proceed with the implementation of the comprehensive plans and move into new programs, there will be many issues of organization and supervision. If we can consistently apply these five criteria, many of the aggravating issues over administrative structure can be met successfully.

THE PREVENTION OF MENTAL RETARDATION

Other subjects, of course, will demand attention in the years ahead. Examples are the supply of technical manpower and programs to meet the preschool needs of deprived children. But now I would like to discuss one of the most exciting prospects of all; namely, the prevention of mental retardation.

For years NARC leaders have pleaded for the support of research, and many of you have responded. Though the needs for

more knowledge remain enormous, what has been discovered is bringing us to the threshhold of a new era--to the time when we can begin to blend an increasing emphasis on the application of knowledge in establishing coordinated community efforts to reduce the incidence of retardation.

Prevention offers a monumental challenge--monumental not only because of the large number of causative factors, biological and environmental, but also because of the astounding rewards that success would bring to all mankind.

During recent years important progress has been made, through research in genetics, biochemistry, neurology, psychology, and other disciplines, in reaching better understandings of human development and the factors that operate to produce defects. Important progress also has been made in introducing preventive measures. Forward steps include measles immunization and testing for inborn errors of metabolism. "High risk" conditions of pregnancy have been identified and treatment prescribed. Ways have been found, such as through Project Headstart, to overcome the adverse effects on intellectual development of cultural and economic deprivation.

But much more appears to be within our grasp. Dr. James A. Shannon, Director of the National Institute of Health,

recently spoke of the "...steadily growing array of tests and procedures for detecting genetic defects that may be passed on by a parent to a child," and concluded that: "These developments are beginning to make it possible for the medical profession to offer a kind of premarital counseling that could ultimately result in a sharp reduction in the incidence of a number of congenital abnormalities, some of which result in severe--and tragic--mental retardation.... Genetic counseling is thus becoming not merely a moral obligation of the medical professional but a serious social responsibility as well...."

Exciting progress is being made not merely on genetic mechanisms but in understanding other internal and external agents and forces that combine to produce aberrant functioning. In advancing knowledge of the organization and functioning of living systems from the sub-cellular to whole organisms, the basis is being found for the detection and avoidance of abnormalities. One can easily sense the excitement that is running through the scientific community as promising new lines of inquiry are revealed and past barriers to progress are removed.

In sight are other helpful developments.

Trial tests are now being made of the first effective vaccine for rubella--commonly known as German measles. The

epidemic that swept across the nation in 1964 and 1965 damaged up to 20,000 infants. It is estimated that as many as 20% of the babies whose mothers contracted the disease during the first three months of pregnancy were afflicted with one or more defects. Rubella outbreaks appear to recur in seven year cycles; so it is anticipated that, with continued emphasis on vaccine development and production, by the time the next epidemic is due in the early 1970s a rubella vaccine will be generally available and used.

The collaborative perinatal study on cerebral palsy, mental retardation, and other neurological and sensory disorders is a longitudinal study of 60,000 mothers and their offspring. Although the study still has many years to go, preliminary findings have been issued that are of great importance in planning programs of prevention. The study has identified numerous conditions associated with prematurity and with abnormally high rates of neurological impairment.

At last the nation is becoming aware of the tragic toll of accidental injury. The National Health Survey reports that over one million children under the age of 15 suffer a severe head injury each year. Data recently gathered in a study in California shows that the rate of severe head injuries to children aged 4 to 18 is 8 per 1,000 per year.

There is mounting concern among neurologists and neurosurgeons that present knowledge is insufficient with regard to the immediate and longer term effects of injury on the brain and as to the best methods of treatment. Early this year an international conference was held, under the sponsorship of the National Institute of Neurological Diseases and Blindness, that identified a number of areas for immediate action, including measures for the prevention or reduction of head injury; establishment of specialized facilities for treatment and rehabilitation; and dissemination of information on all aspects of the problem, including the immediate handling of head injury cases.

The list of causes of mental retardation associated with genetic factors grows steadily. Some 28 inborn errors of metabolism have now been associated with mental retardation. Recent advances include the discovery of homocystinuria, histidinemia, and the identification of the enzyme deficiency in Gaucher's disease. Although the incidence of such disorders taken individually is very low, in the aggregate the numbers become more significant. They become especially significant in identifying and following up on leads to carriers, and thus, through counseling, help to avert future tragedies. They suggest that the time is not too far distant when elaborate

and widespread testing of blood, urine, and tissue, aided by computer systems, will provide great advances in medical diagnosis and prevention.

Several independent avenues of research are yielding results in the development of the means for early detection of abnormal neurological development. Investigations of sleep, for example, are identifying normal and abnormal patterns, and may provide the basis for assessing certain aspects of neurological development in infants. The collaborative perinatal study has produced evaluative procedures that identify sensory and communications disorders at an early stage. Other investigators are working on the development of intelligence tests based on neurological functioning that are free from cultural bias. When coupled with advances in detecting genetic abnormalities, these measures give promise of substantially enlarging early case finding and the prompt institution of treatment.

These newer developments need to be viewed in relation to prior advances in identifying ways to combat mental retardation. It is now possible to catalogue many elements of a comprehensive preventive program, including better maternity care; genetic counseling; case finding; early diagnosis and treatment; detection and treatment of inborn

errors of metabolism; prevention of accidents; poisonings; child abuse; radiation control; surgical procedures; family planning; improvement of socio-economic conditions; and overcoming effects of cultural deprivation.

Taking advantage of the many preventive measures now feasible and emerging will require cooperative efforts of the professions, educational institutions, voluntary associations, private philanthropy, government agencies, business, and the public. Of the many tasks that will need to be done, NARC can bear important responsibilities.

The National Association can, for example, play an active leadership role in formulating blueprints for community action, in serving as an information center, in being instrumental in the production of interpretative films for lay and professional audiences, in organizing institutes for the exchange of current information, and in preparing materials for special audiences.

THE FUTURE ROLE OF NARC

These are some of the tasks ahead. Some involve intricate issues of law, education, architecture, legislation, and government. So it is not surprising that questions are forming in the minds both of veterans and new enlistees in our

movement.

> Is the momentum now great enough that professionals and government agencies will carry on the fight without us?
>
> Has the time passed when the parents of retarded children should be the backbone of this organization?
>
> Is the policy that we should seek to obtain rather than provide services one that in due course will put our local units out of business?

In my judgment the answer to each of these questions clearly is "No." Let us not mislead ourselves on this matter of momentum. Our cause is not like starting a large round boulder down a hill and watching it go. It is more like laboring to roll it uphill. There is another point about which there are misconceptions. One hears, particularly at election time, such nonsense as "once a government program gets started it never gets stopped." The fact is that there is a great ebb and flow in public programs depending upon the emergence of new situations and public attitudes toward meeting them. Some old programs do die and others just fade into ineffective senility.

Today we see striking examples of countervailing forces, such as the backlash effects of riots in civil rights legislation and the impact of war and inflation on Federal programs. President Johnson now is insisting that Federal expenditures be cut well below the level of Congressional appropriations to

help fight inflation, while at the same time Secretary Gardner is trying to assure the scientific community that there will not be a de-emphasis on biomedical research.

I cite these examples not to imply any judgments on inflation, civil rights, or research, but to illustrate the great forces that shape public policy and determine the allocation of resources among many clamoring needs. Only the naive can assume that the comprehensive State plans will somehow be implemented just because they have been reduced to writing or because Federal implementation grants have been made to the States.

The plans did not disclose where to find the money and the qualified people to bring the recommendations into actual programs.

Broadly-based and determined citizen interest is what sustains any uphill fight. The demands for action from many people are necessary to create the environment in which government agencies and professionals will respond. Citizen support is necessary before essential resources become available. This relationship was expressed recently by a distinguished neurologist who said that a lot of people who would work on epilepsy are moving into stroke, "because stroke is where the money is."

The strength of citizen support for the attack on mental retardation has in the past stemmed to a large degree from families and friends who know the problem at first hand. The involvement of parents in large numbers is the envy of other voluntary organizations that have difficulty in securing even a fraction of the energies our people willingly provide. We are referred to with approval as a "grass-roots" organization because that means citizen interest, constituents, and votes.

In our membership of course we need others, too--community leaders, professionals, and just ordinary people who want to help. None of them, however, will provide the cement that binds this organization into a cohesive and hard hitting movement. In my opinion, others can be the eyes, ears, and fingers, but not the backbone!

In the past year there has come about an increasing understanding of the wisdom behind the policy that we should strive to secure services rather than provide them. What is not yet understood is the role of a unit once it divests itself of a particular operation. There is so much that such a unit can do in--

. Seeking out retarded persons and their families who are not now being served. Discovering their needs. Helping them get counsel and advice.

. Learning about program gaps. Is there in your community an activity center? A camp? A recreation program? Checking off the list of needed services and establishing those that are lacking can be just as exciting today as was painting the walls of the basement room in a church for the first nursery class or planning the first bowling night.

The policy of obtain rather than provide explicitly encourages pilot or demonstration projects--with later divesting to other agencies for continued operation.

I recently read a prediction to the effect that many years from now units still would be operating programs, stated as if this would be contrary to NARC policy. Of course units will be operating programs long into the future. It will be unfortunate if they are not. It will be even more tragic, however, if year after year they are the same programs, catering to the same people, with no thought of divesting tasks to appropriate community agencies, and then moving on to other pioneer demonstrations. Surely the gaps we have just considered will be enough for a decade of intensive efforts.

Yet we must not be misled into thinking that the role of the local unit is not changing. It is changing because to old responsibilities are being added others that will call for wider perspectives and new responsibilities. Better services,

architectural planning, the law, governmental organization, and the prevention of mental retardation are illustrative of the subjects that should play a larger part in our actions--in the States and communities and nationally--within the context of rapid social, economic, and scientific change.

We must chart a steady course so that the impact of major external events, such as international crises, inflation, and economic fluctuations, will not set back services or slow the application of research findings. All our efforts must fit together like the mechanisms of a clock, and it must be kept wound so that there will be no loss of that impelling force that keeps the hands going forward. As our clock ticks in the years ahead, the question will be asked "Who will wind it?" The answer is simple, "You will wind it."